



(RESEARCH ARTICLE)



Management of psychological disorders in patients with thalassemia

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Abstract

The purpose of this study is to explore the influence of chronic disease in children and adolescents who are affected by thalassemia major, as well as the behavioral and emotional functioning during their confrontation with the disease. Participants in this study are subjects of age (6-14 years old), the subjects are patients in pediatric ward of Tirana University Hospital Center (QSUT).Thalassemia major is one of the common monogenic hereditary hemoglobin disorders. It results from the absence of a beta-globin chain in the pathway of hemoglobin production. It is now a global public health concern due to changing demographics. The prevalence rate is 1.5% worldwide.[1] Children with chronic illnesses face several challenges that affect them directly. The child or adolescent with a chronic illness sooner or later faces the knowledge that his conditioning has a prolonged course and that he will be under the effect of this conditioning.

Keywords: Thalassemia major; Chronic disease; The quality of life; Behavioral and emotional functioning

1. Introduction

Thalassemia major is one of the common monogenic hereditary hemoglobin disorders. It results from the absence of a beta-globin chain in the pathway of hemoglobin production. It is now a global public health concern due to changing demographics. The prevalence rate is 1.5% worldwide.[1] The child or adolescent with a chronic illness sooner or later faces the knowledge that his conditioning has a prolonged course and that he will be under the effect of this conditioning.[2]Due to the diagnosis, association with another disease, or due to the negative consequences caused by the disease and medical treatment, patients face a difficult physical, psychological, and emotional life. [2]

Some of these changes may be experienced by the patient throughout the stages of the disease while others may only be noticed during a certain stage of the disease. Based on the nature of the chronic disease which accompanies the patient throughout his life, it is reasonable to mention the fact that children and adolescents face various psycho-social difficulties during their coexistence with the chronic disease. Along with age development and maturity, the patient continues his efforts to face the disease which is always getting more and more severe.

Consequently, the importance of developing strategies to face the psycho-social problems that accompany the chronic disease is emphasized.

World psychological research on the adjustment of pediatric patients with chronic illness began in the 1971s, but psychology's interest in health and illness began in earnest about 30 years ago, and more and more research aims to

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understand the relationship between physical illness and psychosocial factors. The quality of life (QoL) of patients with chronic diseases is significantly impaired due to the demands of the disease, the conditions, as well as its clinical treatment. [3]

2. Methodology

2.1. The sample

The sample studied at (QSUT) is considered representative for the population, since patients who are affected by thalassemia all receive onco-hematology services at the Center for Congenital Blood Diseases. In order to form a sample as representative as possible of the target population, data were collected regarding the total number of pediatric patients diagnosed with thalassemia major at the "Mother Teresa" University Hospital Center. Data collection was carried out by reviewing the register of admissions to the Center for Congenital Blood Diseases. The sample included in the study is (n=30).

The sample was selected based on several criteria:

- Pediatric patients must have a diagnosis of thalassemia major
- Patients diagnosed with thalassemia major had to be between 6-14 years of age.
- Patients should have normal cognitive-motor development, able to complete the questionnaire.
- This sample is a sample of convenience and judgment. The age of 6-14 years was chosen, as this selected age has a high level of understanding.

The "quality of life module" for children and adolescents with Thalassemia Major is composed of 33 statements, the sum of which aims to measure the impact of the disease, medical treatment on patients according to the dimensions of functioning, divided into 7 subscales, as follows: [4]

- General fatigue - contains statements such as: "I feel too tired to do things that I usually enjoy doing." and "I feel psychologically tired (not strong)."
- Illness - is mainly related to the physical fatigue experienced by these patients and includes statements such as: "I feel dizzy" and "I am thirsty."
- Family and relationship with peers - measured through three statements which consist mostly of behaviors and relationships with the surrounding environment. The scale contains statements such as: "I can't do things with my family because of my medical treatment." and "I don't feel good when people don't understand my illness."
- Coping with problems caused by the illness - contains statements such as: "I don't like how I feel after taking the medicine" and "I have a hard time remembering to take my medicine."
- Worries about illness - contains 10 statements such as "I worry about having to have an operation in the future." and "I worry about getting infections."
- Perception of the physical appearance - measured through 3 statements which show the reaction of the patient and the people who surround him during the treatment from this disease.
- The scale contains statements such as: "I don't look as big in my body as other children my age." and "I don't like other people to see my scars."
- Communication - the scale contains statements such as: "I find it difficult to express to doctors and nurses how I feel." and "I find it difficult to explain my illness to others." These affirmations consist of communicating with medical staff and parents about how they feel.
- Participants indicate how they experience the illness using a 0 1 2 3 4 Likert scale, where: 0=Never and 4=Almost always, higher scores indicate a lower quality of life for children and adolescents.

2.2. Demographic characteristics of study participants

The data in the table below show that the majority of the participants in the study were from Fieri (20%), 15% of them were from Berat, Lushnja and Tirana.

2.3. Analysis of instrument reliability

The first module of the Quality of Life for chronic disease (ESRD) for children consisting of 33 statements resulted in an alpha coefficient of 0.915, a high value.

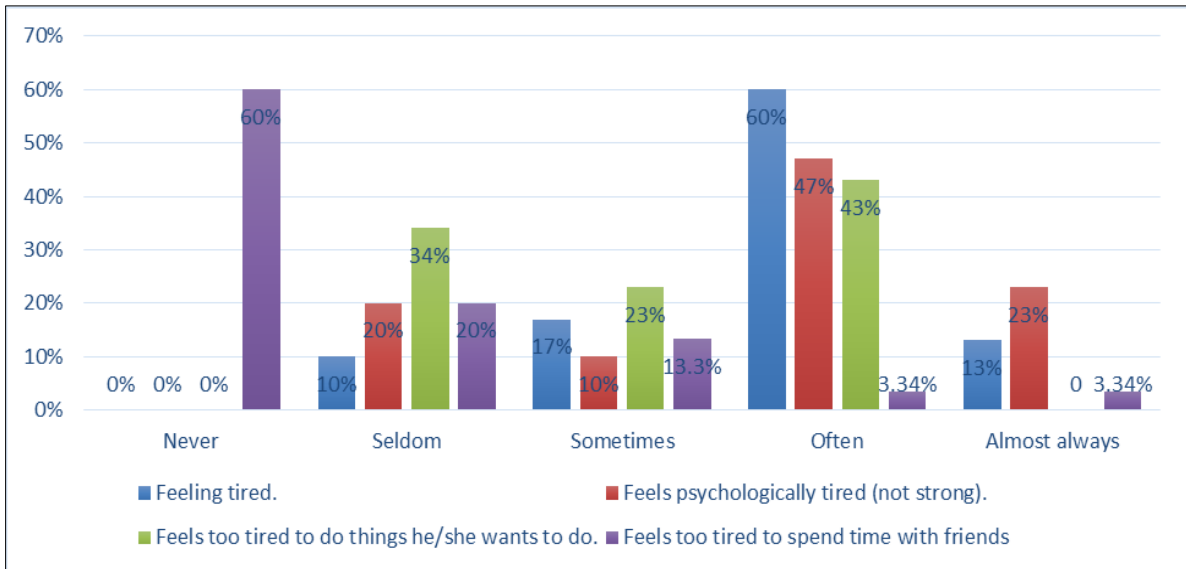


Figure 1 General fatigue

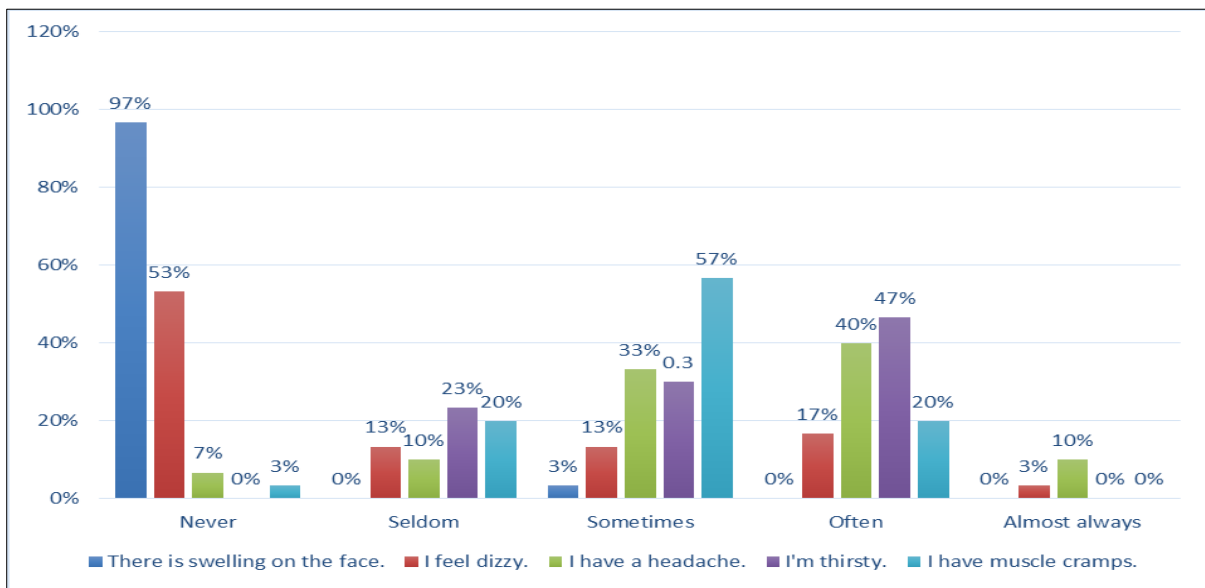


Figure 2 Physical symptoms

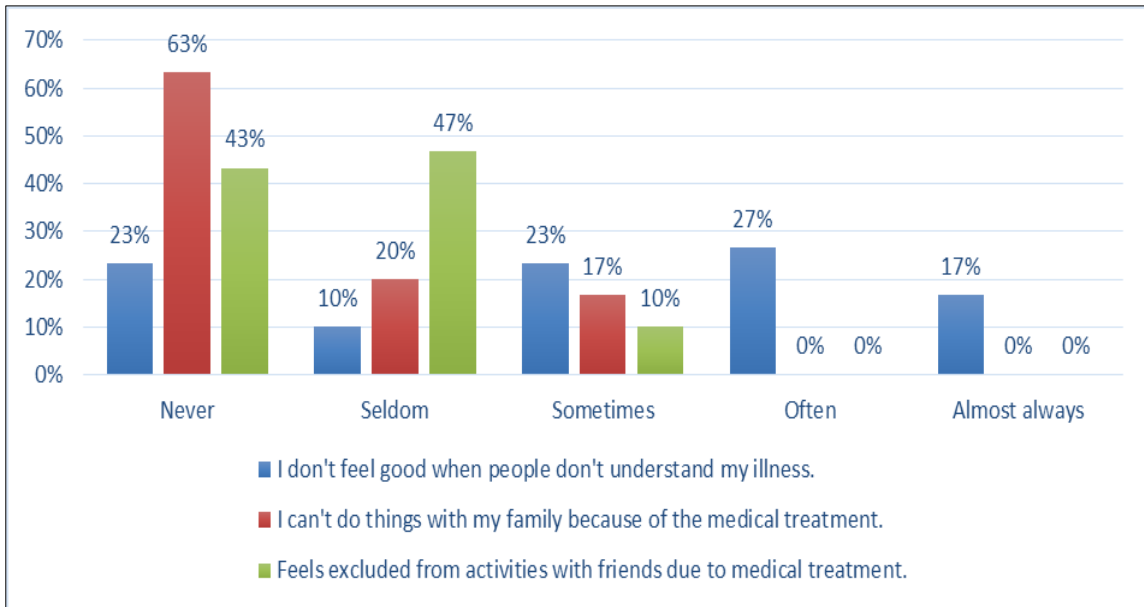


Figure 3 Family and relationship with peers

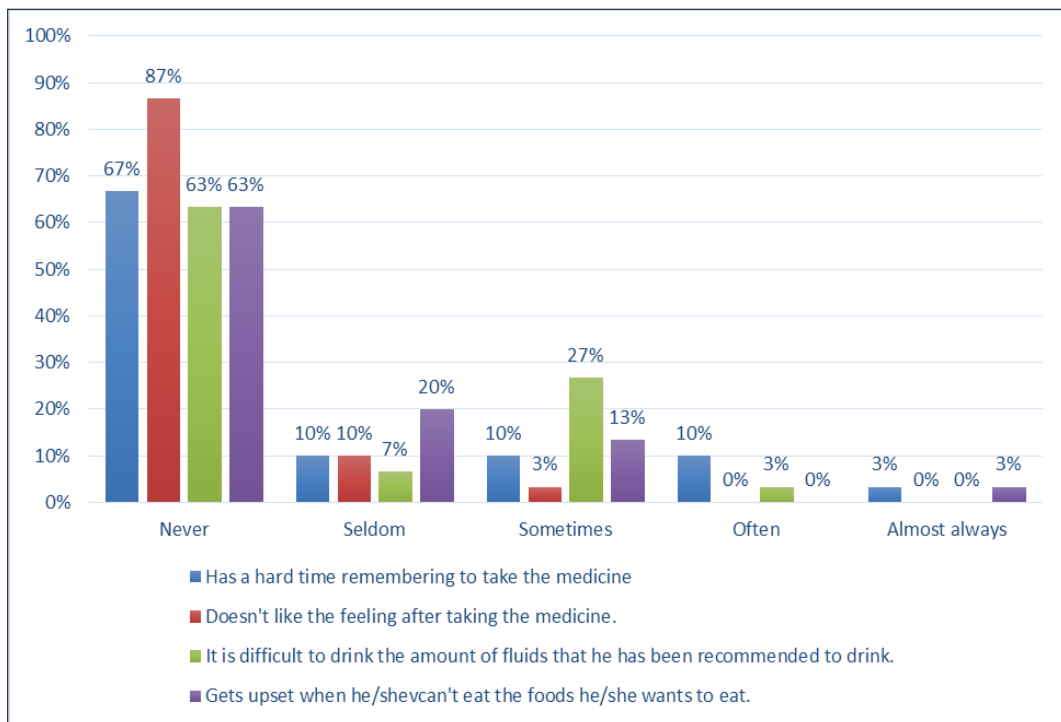


Figure 4 Coping with problems caused by the disease

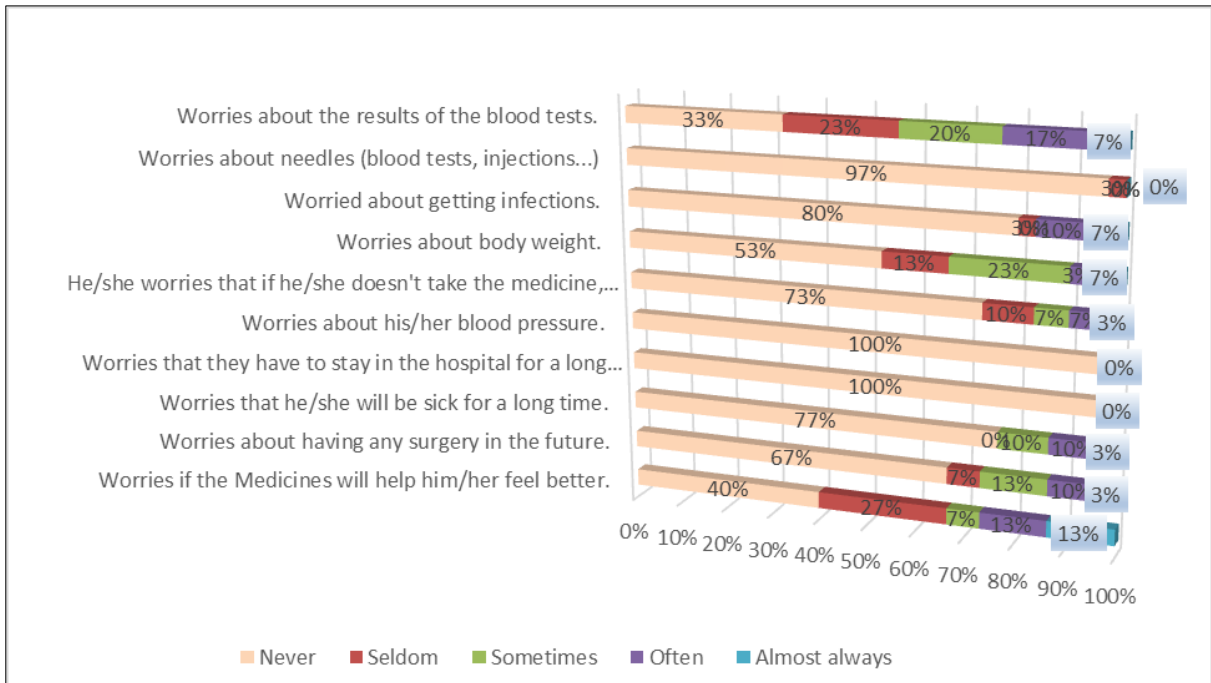


Figure 5 Concerns related to the disease

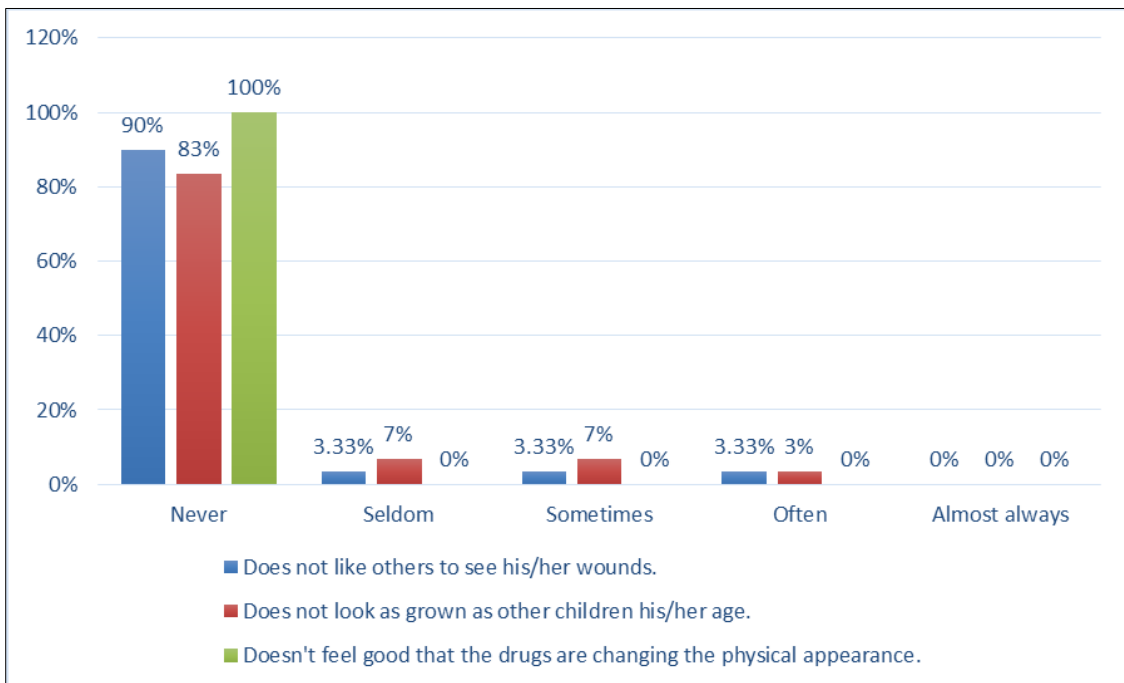


Figure 6 Perception of physical appearance

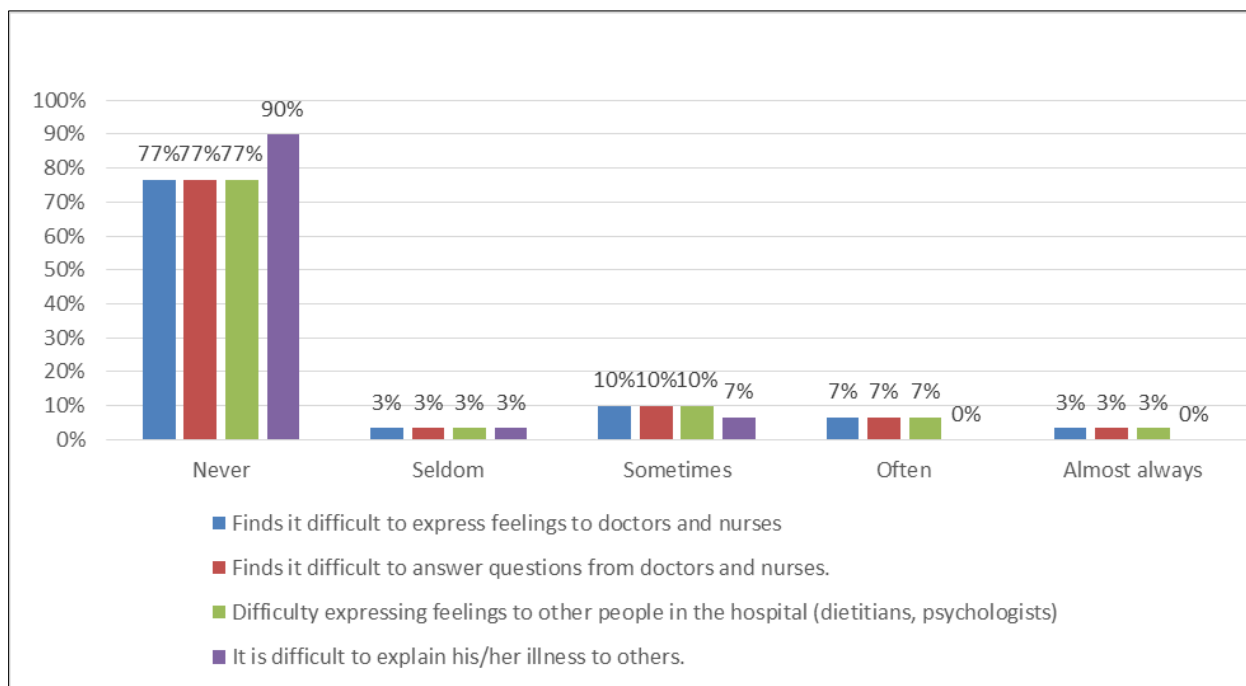


Figure 7 Communication

3. Discussion

Chronic disease can cause psychological problems in childhood as well as lower psychosocial functioning. Thalassemia is one of the diseases with various complications, including physical, social and emotional ones. [5]

From the above results, pediatric patients diagnosed with Thalassemia major encounter difficulties and express an average to low quality of life based on their self-reports. A large part of them, 60%, state that they usually feel tired, and this has a direct impact on their daily activities and functioning, significantly affecting the quality of their lives. Regarding the physical experience of the symptoms, the most common physical concerns are headaches and seizures. These concerns do not have an organic basis and are in the framework of the appearance of somatic (functional) symptoms. They do not feel limited in some aspects in their relationships with family and peers, and a large part of them, 83%, affirm that they are organized and do not have any disruption of their organization due to medication.

From the reports of the concerns of the children included in the study, regarding the disease, it was noticed that the fact that they are always under treatment and have to perform tests from time to time has become common for them and does not bring emotional discomfort. We see that the children and teenagers included in the study have activated the defense mechanism of denial in a very expressive way.

Chronic diseases involve processes that require adaptation. Poor adaptation to their health condition can cause depression, denial, low self-esteem, addiction and disharmony [6][7]. Patients who struggle with thalassemia, which is a chronic disease, experience physical and mental trauma. Like people with other chronic diseases, patients with thalassemia major have to deal with many conditions that the disease itself complicates. In the effort to keep the course of the disease under control, mental health is generally ignored by the patients themselves. [8] [9]

Although the difficulties experienced by patients with thalassemia are reduced by medical treatment, psychosocial problems are of primary importance in these patients.

Regarding the perception of the physical appearance, a large part of the children has expressed that they feel grown up just like other children, this is an indication that their self-concept is not damaged. Self-concept is defined as the determination that a person has towards himself, this perception is formed through the experiences that are lived in the surrounding environment, processed in the cognitive and rational aspect. Self-concept is an organized pattern of thinking about oneself that is a fundamental factor in the formation of personality. It is an organized and relatively stable component that gives stability to the personality, but at the same time the self-concept is dynamic as long as it is vulnerable to even the smallest changes that may occur[10].

Culturally, parents in our country (Albania) tend to be protective, this behavior is generalized even when discussing the disease and its seriousness, with the parents of the children included in the study, clinical conversations were held with each of them, and their tendency was that children affected by thalassemia major were not supposed to know the seriousness of the disease and the way it appears.

4. Conclusion

Due to the preventable nature of the disease, pre-marital examinations should be done in such a way as to focus on the broad promotion of community education to reduce cases. Health care workers should exchange information with patients and address their concerns, to reinforce positive behavior and living a normal life.

Also, conducting a similar study in the future, researching further and including a number of other variables that affect children's adaptation to the disease, would be very important. Recognizing and managing the psychological problems that accompany chronic diseases will help to have optimal results for medical treatment.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

Statement of informed consent

Consent was taken from the parents of hospitalized children included in the study, for using the data of their medical records, providing anonymity.

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